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Breast Cancer Survivors

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INTRODUCTION

Despite general consensus that breast cancer survivors should undergo annual mammography, findings indicate over 1 in 7 women fail to receive a mammogram within 2 years of breast cancer treatment, and that African Americans are almost half as likely to participate in mammography screening as Caucasians. The main objective of this study is to develop and pilot a survey instrument to understand what influences a woman's decision to receive surveillance care following treatment with curative intent for breast cancer and whether different factors are more or less important to different racially defined population subgroups. This study consists of four parts. First we are using information from the literature and focus groups to identify factors influencing a breast cancer's decision to participate in mammography screening. Second, to ensure the cultural and other appropriateness of the survey instrument developed, we have conducted four focus groups: two among Caucasian breast cancer survivors and two among Black breast cancer survivors. Results from these focus groups and the literature are being used to develop a mailed survey to elicit breast cancer survivor's beliefs, social influences and preferences regarding mammography screening programs. In the third phase, we will be pilot testing the survey instrument using a random sample of 100 African American and Caucasian breast cancer survivors. Finally, among the pilot sample, we will describe patient beliefs, social influences, and preferences for program attributes regarding mammography participation and model the relationship of these patient-level factors to mammography participation.

BODY

Human Subjects Protection Approval

Initial project-related efforts were focused on obtaining the necessary approvals for the use of human subjects, both from Henry Ford Health System's (HFHS) Human Rights Committee, Institutional Review Board (IRB), and the Human Subjects Research Review Board (HSRRB) within the Department of the Army. Upon contract initiation (i.e., July 2001), approval was in place for the use of human subjects from the HFHS's Human Rights Committee. Notification of approval of the use of human subjects was received from the Department of the Army's HSRRB on February 27, 2002.

Literature Review

During the first project year, we completed a comprehensive literature review to identify both conceptual models of health care utilization and specific factors previously found to be associated with mammography use. Results from the literature review led to the development of a conceptual model of mammography use among breast cancer survivors. This model, which is depicted in Appendix A, draws heavily upon both the health behavior and economic literature¹⁻⁸, and reflects our theorized importance of not only patient beliefs, social influences, and physician relationship factors, but also patient preferences for different mammography screening program attributes such as the accuracy of the test, the privacy of the results, or the pain associated with testing.

Study Cohort Identification

Efforts during the first project year also included those necessary to identify the study cohort. The target population of our research is women age 40 or older who have survived breast cancer and are eligible to receive follow-up or post-treatment mammography

surveillance care. To identify these women, we used the data available within the Henry Ford Health System's Corporate Data Store, which is a mainframe data warehouse. Data from an electronic cancer registry was used to identify women who were diagnosed with in situ or regional breast cancer between 1/1/95 through 12/31/00. This list of patients was limited to those over the age of 40 who received treatment with curative intent and was stratified by mammogram use in the first 18 months following diagnosis. Information regarding treatment with curative intent and mammogram use was obtained from electronic claims databases. For each of the potentially eligible women, the physician for whom the most visits were incurred was identified. The resulting cohort (N=2052) is serving as the sampling frame for both the focus group and survey research efforts.

Focus Group Research

A random sub-sample of eligible cohort members (N=543) was selected for focus group participation. Once this sample was identified, the corresponding physicians were contacted via letter to obtain permission to contact their patients. For those sample members for whom physician permission to contact was obtained (N=525), letters of introduction were mailed to each potential participant. These letters were followed by a personal telephone call from a project team member, requesting that the woman participate in a focus group. At the time of the call, each potential participant was asked a series of questions to ensure she met the study eligibility criteria and to place her in one of four focus groups, which were distinguished by ethnicity and utilization of mammogram following breast cancer treatment with curative intent. In order to meet our proposed goal of obtaining six to eight participants per group, we recruited twelve persons for each group; the average attendance rate was ultimately 7 persons per group. A detailed summary of our recruitment process is provided in Appendix B.

Each of the focus groups were facilitated by experienced leaders from SPEC Associates, a consulting and management company. The facilitators were selected to ensure that their ethnicity matched the focus group participants. Prior to the focus group sessions, the facilitators were provided written focus group guidelines and overall goals of the discussion (see Appendix C). For each session, two individuals of concordant race per focus group served as scribes. Each session was also audiotaped. The focus groups were carried out successfully, and important information was obtained for further survey development. Appendix D summarizes the focus group discussion findings.

Survey Research

We are currently in the process of finalizing the mailed survey instrument for distribution. Using the conceptual model we developed and the information obtained from the focus groups, the mailed survey is designed to cover the range of factors that may influence a breast cancer survivor's decision to undergo mammography receipt following treatment with curative intent. The survey (see Appendix E) is therefore designed to cover five main types of factors: background characteristics (health status and socio-demographics), individual beliefs regarding disease susceptibility and curability, social influences, physician relationships, and preferences for different screening attributes. We anticipate being able to submit the revised survey for necessary human subject protection processes by August 15.

Next Steps

During the next project period, our efforts will focus on conducting the survey research. This will entail administering the revised mailed survey to 100 African American and Caucasian breast cancer survivors as well as conducting quantitative analyses to determine what factors are associated with a woman's decision to undergo mammograms and whether

these factors differ by race. The process by which the mailed surveys are distributed will be similar to the method that was utilized to recruit focus group participants. Once the appropriate sample is identified, the potential participants' physicians will be contacted via letter to obtain consent to contact the specific patients mentioned. When consent is received, a packet will be sent out to the potential participant, which will include a letter of introduction, informed consent form, survey, and self-addressed/stamped return envelopes. As the surveys are returned, the information will be entered into an Access database using scanning technology. Statistical analyses will be performed to examine, among other issues, the relative importance of factors influencing mammography use controlling for patient socio-demographic factors, attitudes toward risk, treatment received, and family history of breast cancer.

KEY RESEARCH ACCOMPLISHMENTS

- Conducted comprehensive literature review to identify factors that influence a breast cancer survivor's decision to participate in mammography screening. This review included identification of specific factors as well as conceptual models of health behavior.
- Developed a theoretical model of mammography use upon which to design the pilot survey. This model encompasses patient beliefs, social influences, physician relationship factors, and patient preferences for different mammography screening program attributes.
- Identified a cohort of 2052 breast cancer survivors who met the study eligibility criteria. These women now constitute the sampling frame for both the focus group and survey research efforts.
- Conducted four focus groups to identify the factors breast cancer survivors consider when deciding whether or not to have a mammogram and to obtain feedback on initial survey instrument.
- Prepared detailed summaries of focus group discussions and resulting themes.
- Developed revised mailed survey, which is now under final review by all study investigators.

REPORTABLE OUTCOMES

- Abstract submitted to the Era of Hope 2002 Department of Defense Breast Cancer Research Program Meeting, entitled, "Understanding Racial Disparities in Mammography Use among Breast Cancer Survivors." Please see Appendix F.
- The conceptual model of mammography use developed as part of this research effort has been adapted for use to evaluate colorectal cancer screening decisions among a general population. This conceptual model formed the basis for an R21 submission to the National Cancer Institute to evaluate colorectal cancer screening participation among diverse primary care populations.

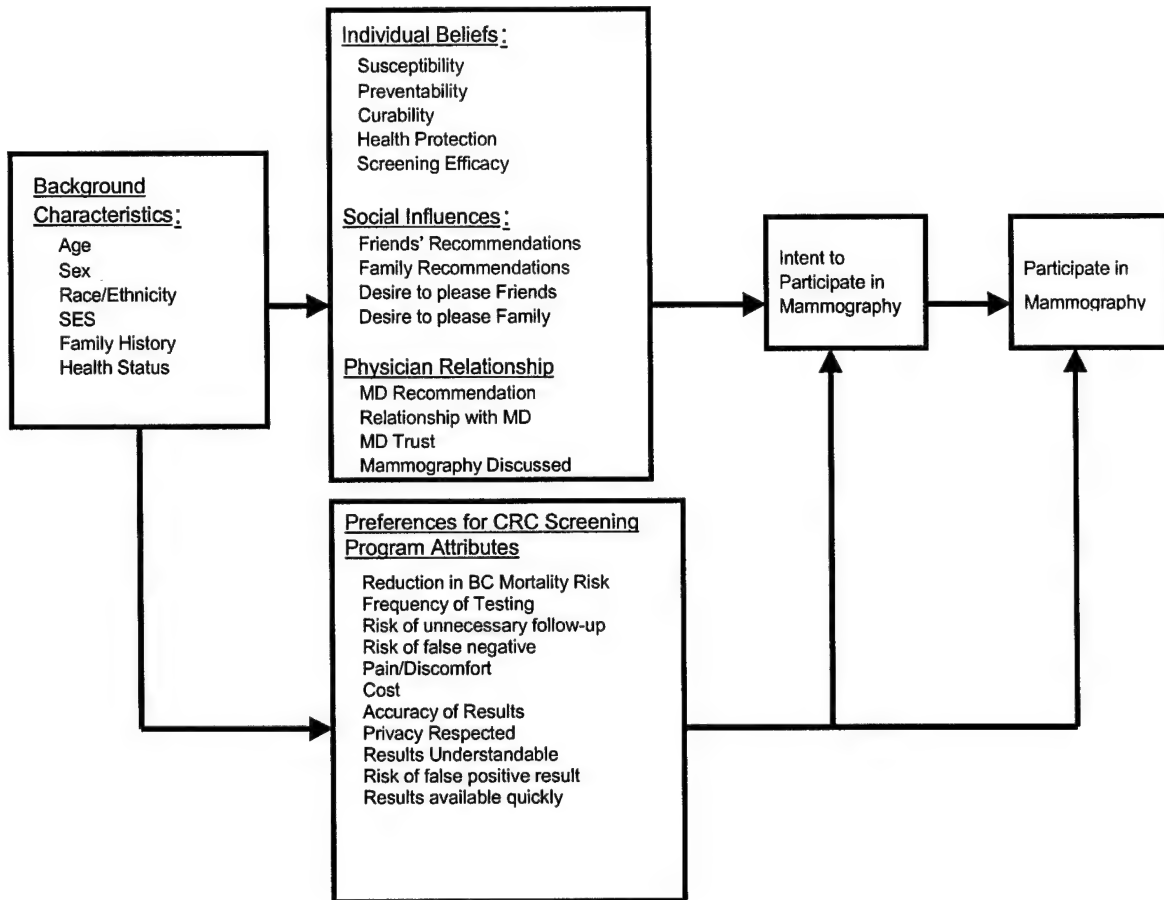
CONCLUSIONS

We believe our efforts under this developmental award have been quite productive. These efforts have resulted in the formation of a conceptual model of mammography use and the development of a mailed survey to understand the factors associated with the decision to undergo mammography surveillance among racially diverse populations. Furthermore, our efforts have served as the conceptual basis of a grant application to the National Cancer Institute. We look forward to completing the survey research portion of our project over the next few months.

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Appendix A:
Conceptual Model of Mammography Screening. (Adapted from Myers et al. 1994)



Appendix B: Focus Group Enrollment Process

Women's Health Project (DOD)

- Random sample of 588 patients aligned to 52 physicians identified as potentially eligible for focus group participation
- 543 patients with physician approval were mailed introductory letters
- 18 refused by patient phone call or mail
 - 15 = declined by mail
 - 1 = call (not well enough to attend)
 - 1 = call (no transportation)
 - 1 = call (patient deceased)
- Remaining 525 eligible for telephone contact, and stratified by race and mammography use

Caucasian: Yes Mammogram

n=289

13 = mail/call refused

115 = TOTAL calls made

16 = refused

71 = no contact (left message)

13 = unavailable at scheduled time

1 = ineligible (said doesn't have cancer)

2 = ineligible (HFHS employees)

12 = AGREED to attend

8 ATTENDED

162 = not used

Caucasian: No Mammogram

n = 55

2 = mail/call refused

104 = TOTAL calls made

15 = refused

17 = no contact (left message)

2 = unavailable at scheduled time

1 = ineligible (said she had regular mammo)

1 = ineligible (HFHS employee)

1 = language barrier

4 = non working number

12 = AGREED to attend

6 ATTENDED

0 = not used

African-American: Yes Mammogram

n = 141

2 = mail/call refused

40 = TOTAL calls made

2 = refused

3 = non working number

1 = agreed/but FG filled

2 = unavailable at scheduled time

20 = no contact (left message)

12 = AGREED to attend

9 ATTENDED

99 = not used

African-American: No Mammogram

n = 40

1 = mail/call refused

97 = TOTAL calls made

5 = refused

17 = no contact (left message)

1 = unavailable at scheduled time

1 = ineligible (HFHS employee)

3 = deceased

12 = AGREED to attend

6 ATTENDED

0 = not used

Appendix C: Focus Group Guide

Focus Group Questions for Survey Development

Facilitator: *SPEC Associates*

Assistants: _____

I. WARM-UP AND EXPLANATION (10 minutes)

A. Introduction

1. Good afternoon. My name is _____. I work with a company called SPEC Associates that conducts focus groups on behalf of organizations like Henry Ford Health System. This is _____ and _____. They will be the assistants today.
2. Thanks for coming. We appreciate you taking time out of your day to help us. As breast cancer survivors, you have a unique and exciting opportunity to share your thoughts and experiences so that we can learn about how to improve health care for women in the future.
3. Your presence and participation are important. Your thoughts and comments about getting a mammogram and a survey we are developing will be valuable in helping to provide future information on breast care issues. This focus group will be a two-part process: there will first be open-ended questions and then there will be a discussion and review of the survey you received when you signed in earlier.
4. We feel that everyone's opinions and comments are important. While there are a lot of questions to cover in a relatively short amount of time, we will try our best to hear from everyone. Please know that if we have to move on to a new topic it's not that we don't want to hear what you have to say, but that we have to keep moving in order to cover everything.

B. Purpose

1. What we are doing here today is called a focus group. It's a discussion to find out your opinions – like a survey.
2. I am interested in all of your ideas, comments and suggestions.
3. Each of you is very important and all of your comments – both positive and negative – are welcome.
4. There are no right or wrong answers.
5. Please speak up – even if you disagree with someone else here. It's important that I hear what each of you thinks.

C. Procedure

1. We will be audiotaping our discussion. Everything you say is important to us, and we want to make sure we don't miss any comments. Later we'll go through all of your comments and use them to prepare a report on our discussion. However, all of your comments are confidential and will be used only for research purposes. Nothing you

say will be connected to your name. Also, if any questions make you uncomfortable, feel free not to answer them.

2. You don't have to wait for me to call on you but please speak one at a time, so the tape recorder can pick up everything.
3. We have many topics to discuss so I may change the subject or move ahead. Please stop me if you want to add anything.

D. **Self-Introductions (Ice Breaker)**

1. Please tell us your name and your dream vacation.

II. GENERAL THOUGHTS ABOUT MAMMOGRAMS

BARRIERS

1. What do you think are the most important reasons why a woman who has survived breast cancer may choose **not** to receive a mammogram?
- 2a. Are there things that a doctor could tell a woman who has survived breast cancer that would make her **more likely** to get a mammogram?
- 2b. Are there things that a doctor could tell a woman who has survived breast cancer that would make her **less likely** to get a mammogram?
- 3a. What kinds of **good things** do women hear from family members or friends about **getting a mammogram** once they have been diagnosed with breast cancer?
- 3b. What kinds of **bad things** do women hear from family members or friends about **getting a mammogram** once they have been diagnosed with breast cancer?
4. What do you think are some fears breast cancer survivors have about getting a mammogram once they have been diagnosed with breast cancer?

PROBES:

What do you think would be some things that would keep a woman from getting a mammogram, even if she wanted to get one?

Do you think that some breast cancer survivors don't get a mammogram because they are **afraid to think about cancer**?

Do you think some breast cancer survivors don't get a mammogram because of the **discomfort** associated with a mammogram? the **embarrassment**? the **cost**? the **inconvenience**?

- 5a. Are there people in a breast cancer survivor's life who can **encourage** her to get a mammogram? Who are they and how do they do that?
- 5b. Are there people in a breast cancer survivor's life who can **discourage** her from getting a mammogram? Who are they and how do they do that?
6. To what extent do you think fear or mistrust of the medical establishment keep breast cancer survivors from getting a mammogram?

MOTIVATIONAL ITEMS

1. Are there things that you think would help motivate breast cancer survivors to get a mammogram?

PROBE: Are there other things that might motivate a breast cancer survivor to get a mammogram?

2. What do you think messages designed to encourage breast cancer survivors to get a mammogram should say?
3. Do most breast cancer survivors think that the results of a mammogram are reliable?

PROBE: On a scale of 1 to 10 (1 = not reliable, 10 = very reliable), how would you rate the reliability of mammogram results?

III. SURVEY

1. **Please look at the first page of the survey.**

Are the instructions on how to complete the survey clear?

If not, which words would you use to give instructions for completing the survey?

2. **Now, let's go to the first question.**

- a. Are any of questions 1 – 4 unclear to you?

If so, how would you ask these questions?

- b. How comfortable would you feel in answering questions 1-4?

- c. What makes you feel comfortable or uncomfortable about answering these questions?

3. Now, let's look at the section called "About Your Physician."

- a. Is the phrase "Think about the physician that you usually see about your breast care" clear to you?
If not, which word(s) would you use instead?
- b. Are any of the questions unclear?
If so, how would you ask these questions?

4. Now, let's look at the section called "Your Opinions."

- a. Is the meaning of the words "Your Opinions" clear to you?
If not, which word(s) would you use instead?
- b. Are the instructions on how to complete questions 7 and 8 clear to you?
If not, how would you give the instructions?
- c. Are questions 7 and 8 unclear?
If so, how would you ask these questions?
- d. How comfortable would you feel about answering questions 7 and 8?
- e. What makes you feel comfortable or uncomfortable about answering these questions?

5. Now, let's look at the section called "Your Preferences."

- a. Is the introduction to the "Your Preferences" section clear?
If not, which words would you use to introduce this section?
- b. Are the instructions on how to answer this section clear to you?
If not, how would you give the instructions?
- c. How comfortable would you feel about answering questions 9 and 10?
- d. What makes you feel comfortable or uncomfortable about answering these questions?
- e. What additional questions would you ask about opinions regarding mammograms?
- f. How hard would it be to fill out this section?
If you think it would be hard, what would make this question easier to fill out?
- g. If you think it would be easy, what makes it easy to fill out?
- h. Are there features that should be on or off the list?
If so, which ones?
- i. Let's look at the word "quickly" in 9f. What does quickly mean to you?

j. Let's look at "quickly" again in **9p**. What does quickly mean to you here?

k. Are there any words or phrases in this section that are not clear to you?
If so, which words or phrases are not clear?

6. Let's turn now to "Your Background."

a. How do you feel about surveys that include these types of questions?

b. How comfortable or uncomfortable would you feel about answering these questions?

c. What makes you feel comfortable or uncomfortable about answering these questions?

d. Are there any questions that should be omitted?
If so, which ones? Why?

7. GENERAL THOUGHTS ABOUT THE SURVEY

a. What makes you feel comfortable about completing the survey?

b. Is there anything that would make you feel uncomfortable about completing the survey?

c. How does the layout of the survey look to you?

d. What would be some ways to improve the layout?

e. How do you feel about the survey overall?

f. If the survey were mailed to your home with a self-addressed postage-paid envelope, do you think you would complete and return the survey?

Appendix D: Focus Group Summary

BARRIERS

	1. What do you think are the most important reasons why a woman who has survived breast cancer may choose <u>NOT</u> to receive a mammogram?	2a. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>MORE LIKELY</u> to get a mammogram?	2b. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>LESS LIKELY</u> to get a mammogram?
Caucasian – USERS	<ul style="list-style-type: none"> • Mam. not accurate in not showing cancer • False negatives • Mam misread by radiologist – wasn't brought to anyone's attention. • Didn't show cancer • Person who examine may not be good. • Have to be aggressive with the docs • Pain • Inaccuracy in reading • Type of cancer was difficult to see on mam • Depends who does the exam – some techs don't take careful reading • One lady had double mast., so didn't need mam anymore (per doc's orders) bc breast tissue was removed. Still worries about cancer coming back. 	<ul style="list-style-type: none"> • Cancer found early • Try to encourage • Encourage by telling you it would give you peace of mind • Tell people about latest research findings about accuracy of mams bc some docs not reassuring • More upfront about latest research re breast cancer – statistics, facts. • Doc keep checking on patients – need more reminders • Doc remind people about recurrences if they have had cancer 	<ul style="list-style-type: none"> • Doc says she didn't need bc of mast. – but she still worries about recurrence • Had info [?] it's gone – don't worry about it • Want someone that is concerned about their health
Caucasian - NON-USERS	<ul style="list-style-type: none"> • Afraid to come back – fear • Once you had it cured – wouldn't get again • Financial reasons • Think that it might not come back • If it comes back, it might be worse – couldn't deal with it again. 	<ul style="list-style-type: none"> • "I'll see you 2 weeks after your next mam" • Letting them know that cancer can exist even though there are no lumps. • Schedule appt right after mam to see doc • Schedule regularly, routinely • Doc should just reiterate • Having info that can tell you mam was good • Pre-scheduled mams – problem with scheduling • Had bilateral – doesn't have to have mams anymore • Focus on early detection 	<ul style="list-style-type: none"> • Everything fine • Doc tells her she's fine, so he may give her false sense of security that everything is gone • Might say other health problems are more important
African-American – USERS	<ul style="list-style-type: none"> - could not think of a reason why women would not want to get a mam. - fear - heartless, painful, the way technicians handle your breast - if the breast is sore, and the person giving it is insensitive about the way they are handling it. - staff/technician rude, unfriendly, very insensitive - don't want to deal with it 	<ul style="list-style-type: none"> - Cancer can come back - if a close family member has it, the breast cancer is more likely to come back - genetic 	<ul style="list-style-type: none"> - may not find cancer in mam., even if it is there. - not likely you'll get it again - if physician is a man, he may say it is not necessary

African-American – NON-USERS	<p>1. What do you think are the most important reasons why a woman who has survived breast cancer may choose <u>NOT</u> to receive a mammogram?</p> <ul style="list-style-type: none"> - could not think of a reason why women would not want to get a mam. - fear - discomfort - painful to them - rude or unfriendly staff/technician administering the mam. 	<p>2a. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>MORE LIKELY</u> to get a mammogram?</p> <ul style="list-style-type: none"> - prevention, early detection - cancer can come back 	<p>2b. Are there things that a doctor could tell a woman who has survived breast cancer that would make her <u>LESS LIKELY</u> to get a mammogram?</p> <ul style="list-style-type: none"> - can't imagine anything that could be said
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	3a. What kinds of GOOD THINGS do women hear from family members or friends about getting a mammogram once they have been diagnosed with breast cancer?	3b. What kinds of BAD THINGS do women hear from family members or friends about getting a mammogram once they have been diagnosed with breast cancer?	4. What do you think are some fears breast cancer survivors have about getting a mammogram once they have been diagnosed with breast cancer?
Caucasian – USERS	<ul style="list-style-type: none"> • Family just assumes they'll go • Tell them the outcome • Family can be interested when told that she went. • One said most of her family assumes that she will take the initiative herself • Wear pink ribbon pens (breast cancer survivors helping others) • Don't need to encourage bc they assume you are doing the right thing and going. • Mostly they [fg members] encourage other people to go and get them bc they had had cancer. • Breast cancer survivors encourage other people more 	<ul style="list-style-type: none"> • Pain • Will it hurt • COST – money worries, insurance • Delay getting exam bc of insurance coverage • Will insurance cover cost of breast cancer? • Concerns about insurance programs changing 	<ul style="list-style-type: none"> • Fear of cancer coming back • Fear of radiation exposure over lifetime • Time off of work • Worry about not being able to work • Don't have time to take off work.
Caucasian - NON-USERS	<ul style="list-style-type: none"> • Lucky you got diagnosis • Remind her to take care of her health • Care for her health • Control of her health • Happy they survived – 1st cancer and happy things are going well • Expressing that they're happy and relieved that they got a mam. 	<ul style="list-style-type: none"> • Waiting for results, they bring this to the forefront. • Expressing own anxiety that they don't like mams • Talk about their own anxiety • Cost – can we afford this again 	<ul style="list-style-type: none"> • That it is back • Painful • Activating the post-traumatic experience • After diagnosis and mam – old feelings and fears come back about cancer
African-American – USERS	<ul style="list-style-type: none"> - early detection is key - continue to get them - it could save your life - reminders to get mam. 	<ul style="list-style-type: none"> - discomfort - someone died from it. That can be very discouraging. - It hurts 	<ul style="list-style-type: none"> - fear it will come back, go to other breast - too young - spread to other areas
African-American – NON-USERS	<ul style="list-style-type: none"> - You are going to be all right - Asking if it's time to get your mam. - survival - encouragement / force / threats - reassurance - advice - example (i.e., someone who has had cancer and repeat mam.s and are fine) - necessary - reminders to get mam. 	<ul style="list-style-type: none"> - discomfort - fear social life and love life will change 	<ul style="list-style-type: none"> - fear it will come back, go to other breast - too young - may not live long - fear of suffering - not attractive to a man - fear of treatment and treatment side effects

	PROBES: What do you think would be some things that would keep a woman from getting a mammogram, even if she wanted to get one?	Do you think that some breast cancer survivors don't get a mammogram because they are afraid to think about cancer?	Do you think that some breast cancer survivors don't get a mammogram because of the discomfort associated with a mammogram?
Caucasian – USERS	<ul style="list-style-type: none"> • Radiation exposure • Cost issue – very complicated to get a free mam (one was out of work and getting free mams but was too much red tape. Waited until she had a job again.) • Transportation problems • Babysitting problems • Just too busy – just keep putting it off • If feel nothing wrong, why go • Feel all right, don't feel sick • Just don't like the exam itself 	<ul style="list-style-type: none"> • Fear of coming back (most agree true) • Afraid of diving • Live for life 	<ul style="list-style-type: none"> • Pain delay getting, but still getting the test <p>The embarrassment? Don't feel embarrassed, older woman</p> <p>The cost? Cost – yes can be the issue.</p>
Caucasian - NON-USERS	<ul style="list-style-type: none"> • Not having ready access to clinic – scheduling appts in advance • Having to drive a long way • Other responsibilities, kids, elderly parents, work • Financial concerns • Too busy with everyday things, get caught up • Problems in scheduling one • Might not want to know results 	<ul style="list-style-type: none"> • Don't go, block out, don't have to deal with it. 	<ul style="list-style-type: none"> • Just an excuse • If don't have insurance, cost would be an issue • The responsibilities, too busy <p>The embarrassment? No, not an issue</p> <p>The cost? if don't have insurance, could would be an issue</p> <p>The inconvenience? The responsibilities, too busy.</p>
African-American – USERS	<ul style="list-style-type: none"> - Taking the time to get it scheduled - afraid - can't be on hold for hours - taking time off work - type of insurance / don't have insurance - if someone says that they are too young (age) 	<ul style="list-style-type: none"> - yes - denial, don't want to know - there may be scar tissue as AA keloid and mass may be misinterpreted 	<ul style="list-style-type: none"> - everyone expects discomfort (breast stays sore) <p>The embarrassment? No. What is embarrassing about it? Not big boobs?</p> <p>The cost? if don't have insurance, could would be an issue</p> <p>The inconvenience? The responsibilities, too busy.</p>
African-American – NON-USERS	<ul style="list-style-type: none"> - t.v. ads - don't want to know - scared of what they might find - maybe think she's too young - talking w/ people with cancer and watching media 	<ul style="list-style-type: none"> - Yes, just don't want to know 	<p>yes</p> <p>The embarrassment? Nothing embarrassing</p> <p>The cost? yes</p> <p>The inconvenience? Yes, but if you've been through it once, maybe not.</p>

	<p>5a. Are there people in a breast cancer survivor's life who can ENCOURAGE her to get a mammogram? How do they do that?</p> <ul style="list-style-type: none"> • Yes, but don't usually hear anything • Docs constantly reminding. Primary doc – keeps after her when she goes in for visit. • Family, daughter • Doc – just give them another referral • If didn't get one – she's sure family would be after her • Other cancer survivors (one said she never even talks about it with her friends) • PCPs (for example, if someone comes in for a cold, docs can ask about mams). • Some friends who have had bc but don't talk about it. 	<p>5b. Are there people in a breast cancer survivor's life who can DISCOURAGE her from getting a mammogram? How do they do that?</p> <ul style="list-style-type: none"> • Wouldn't listen to anyone who would discourage them • Family member – denial of her having cancer (her husband) • Alternative cancer treatment, those type of publications may discourage people from going to a regular doc. • Articles/tv shows that try to encourage different types of treatment that may not be mainstream. 	<p>6. To what extent do you think fear or mistrust of the medical establishment keep breast cancer survivors from getting a mammogram?</p> <ul style="list-style-type: none"> • Sometimes • Even if cancer there?? • Cancer was hard to detect and they didn't see right away • Doc office had a lot of inaccuracies, misreads. • Clinic sent letter said it wasn't fine – misread reading • Docs don't know everything.
<p>Caucasian – USERS</p>	<ul style="list-style-type: none"> • Children – concerned about moms. Want them to take care of themselves • Spouses – remind you, nag • Good friends – "I've had mine, have you had yours?" Could suggest getting mams together. • mom • Work environment – have mam screening weeks. Work can also encourage by offering to pay for them. 	<ul style="list-style-type: none"> • Anyone in your family who puts it down (find other excuses to tell you not to go) • Media – publicity that mam's cannot catch a lot of cancer cases. • "Do you have to?" • "Oh that again?" 	<ul style="list-style-type: none"> • Don't get discouraged, you should trust your doc • Their experience hasn't been a negative one • Fear – postpone mams • Once you've survived, if it wasn't a good experience. You might feel different • Maybe cultural issues would make other women feel different.
<p>Caucasian - NON-USERS</p>	<ul style="list-style-type: none"> - Yes, family members, doctor, friends, children, siblings - family members who have survived cancer - focus / support groups - talking about cancer, bringing it out in the open - walkathons (e.g., Relays for Life) 	<ul style="list-style-type: none"> - caring friends not wanting you to go through changes as they've seen in the past. - Friends may say you really don't need that - Friends or family who saw the anguish you went through the first time may suggest herbs or alternative medicine. - Spouse may see what it cost us before and may say to just leave it in the Lord's hands. 	<ul style="list-style-type: none"> - mam. misread - if someone doesn't have a full understanding from the medical person as to options or x-ray, etc. (they don't take the time to explain), one may say why should I go. - not suggest alternative treatments - not found by mam. but by patient
<p>African-American – USERS</p>	<ul style="list-style-type: none"> - Yes, family friends, when they tell you how much you mean to them - Children who ask questions showing concern - drive if no transportation - money - check exam schedule - make loving statements (e.g., love you, can't let anything happen to you) - show concern for wives - reiterate what can happen if don't get a mam. 	<ul style="list-style-type: none"> - negative friends and family giving bad advice - so-called friends who don't really care about you. 	<ul style="list-style-type: none"> - Whether or not they will be thorough in getting it all - Doctor or person there not having a personal touch or sensitive to them. - incorrect advice - question if they got it all the cancer - provider and/or staff's negative attitude - bad experience with treatment
<p>African-American – NON-USERS</p>			

MOTIVATIONAL ITEMS

	1. Are there things that you would think would help motivate breast cancer survivors to get a mammogram?	2. What do you think message designed to encourage breast cancer survivors to get a mammogram should say?	3. Do most breast cancer survivors think that the results of a mammogram are reliable?
Caucasian – USERS	<ul style="list-style-type: none"> When go to see doc – get mam right then. System of making so many appts don't book 6 mos. In advance, only book 3 mos in advance so you have to call back. Just a lot of calling to try to get an appt. Make the appt making simpler, less complicated. Want better access to getting mams Want better reminder system 	<ul style="list-style-type: none"> "I got mine – did you get yours" Point out it should be a part of routine care You said routinely do Remind them of how scared family was when you just went through this the 1st time. Try not to put them through that again. Encourage people to attend American Cancer Society Media-related messages. Breast cancer awareness month, PSAs, etc. Keep telling people to remind them 	<ul style="list-style-type: none"> Scale of 1-10 (10=very reliable): 8, 7, 6, 8, 9, 7, 8, 9 To some degree Human error ½ got diagnosed bc of mam [Most of the group thought they were reliable] more rare cancer was difficult to detect first thought they were fool-proof but they didn't fine. Now she knows they can make mistakes. Never had worried. Believed in mams strongly, when surgeon told her she had cancer she didn't believe him, said her mam was clear and they were wrong.
Caucasian - NON-USERS	<ul style="list-style-type: none"> Just receiving the slip of paper to go to radiology Get immediate results – get mam and results the same day Make an appt to see doc right after Knowledge that early detection is best See doc every 3-4 months Mailed reminder helpful. Doesn't let you forget. Have mams read the same day – very nice – don't have to wait for results (she goes to Karmonos breast cancer clinic – don't have the anxiety of waiting). 	<ul style="list-style-type: none"> Presence of micro calcifications can be an indicator of cancer. A lot of women don't know about this. 40% microcalcifications can cause cancer (these are not lumps) Magazines aren't telling women about this Messages to educate women more Mam now have ability to pick this up Mam's can pick up these things now Can have breast cancer and may not have a lump Pick up early enough – more available New advances going on in medical field People need to know that breast cancer is much more treatable today, and the survival rate is much better that it was...need to know about survival rates, etc. 	<ul style="list-style-type: none"> Scale 1-10: 10, 8, 10, 8, 9, 8 Does people who are breast cancer survivors get more care than the typical person going for annual check ups. Breast cancer survivors' mams might be more scrutinized. Mams may get better attention, don't have to wait and see

	1. Are there things that you would think survivors to get a mammogram?	2. What do you think message designed to encourage breast cancer survivors to get a mammogram should say?	3. Do most breast cancer survivors think that the results of a mammogram are reliable?
African-American – NON-USERS	<ul style="list-style-type: none"> - insistent doctor - yes, they are alive now and can live on - not willing to leave husband to remarry, buy younger wife a new house 	<ul style="list-style-type: none"> - don't say anything about death/dying - it is time to get checked - your life depends on it - have several breast cancer survivors who have been alive 20-40 years after time to get your mam. - statistics that there are more survivors than those dying from the disease - not only kind of cancer - you're not a doctor 	<ul style="list-style-type: none"> - Most - 9, 9, 8, 10, 7, 10

Appendix E: Draft of Revised Mailed Survey

WOMEN'S HEALTH AND USE OF HEALTH SERVICES

INSTRUCTIONS: This survey asks you for your views about your health, your doctor, and getting a mammogram. Unless otherwise instructed, please indicate the item that best answers the questions by filling in the circle next to the item. You may use a pen or pencil to complete the survey.

ABOUT YOUR HEALTH

1. In general, would you say your health is: ☐ Excellent
☐ Very Good
☐ Good
☐ Fair
☐ Poor
2. Please fill in the answer that best describes whether each of the following statements is true or false about your general health.

Select one answer on each line.

	Definitely True	Mostly True	Not Sure	Mostly False	Definitely False
a) I think my health will be worse in the future than it is now.					
b) In the future, I expect to have better health than other people I know.					
c) I expect to have a very healthy life.					
d) I expect my health to get worse.					
e) My future will be unhealthy.					
f) Good health is in my future.					

3. During the past month, have you often been bothered by feeling down, depressed, or hopeless?
☐ YES ☐ NO
4. During the past month, have you often been bothered by little interest or pleasure in doing things?
☐ YES ☐ NO

ABOUT YOUR BREAST CARE DOCTOR

5. Think about your doctor that you see most often for your breast care.

	Always	Usually	Sometimes	Never
a) Does your doctor give you enough time to explain the reasons for your visit?				
b) When you ask questions, do you get answers that are understandable?				
c) Does your doctor take enough time to answer your questions?				
d) Does your doctor ask you about how your family or living situation might affect your health?				
e) Do you get as much medical information as you want from your doctor?				
f) When you see your doctor, do you have questions about your care that you want to discuss but do not?				
g) Are you involved in decisions about your care as much as you want?				

6. Thinking about the doctor that you see most often for your breast care:

	Strongly Agree	Agree	Neither Agree nor Disagree	Disagree	Strongly Disagree
a) I doubt that my doctor really cares about me as a person.					
b) My doctor is usually considerate of my needs and puts them first.					
c) I trust my doctor so much I always try to follow his/her advice.					
d) If my doctor tells me something is so, then it must be true.					
e) I sometimes distrust my doctor's opinions and would like a second one.					
f) I trust my doctor's judgements about my medical care.					
g) I feel my doctor does not do everything he/she should about my medical care.					
h) I trust my doctor to put my medical needs above all other considerations when treating my medical problems.					
i) My doctor is a real expert in taking care of medical problems like mine.					
j) I trust my doctor to tell me if a mistake was made about my treatment.					
k) I sometimes worry that my doctor may not keep the information we discuss totally private.					

YOUR PREFERENCES

7. Choosing whether or not to get a mammogram can be difficult. Refer to the list of exam features in Question 8 below and enter only **ONE LETTER** in each box.

Of the features listed below in Question 8 that are "Important" to you, which **TWO** are the **MOST IMPORTANT** to you when choosing whether or not to get a mammogram?

☐ AND ☐

Of the features listed below in Question 8 that are "Not Very Important" to you, which **TWO** are the **LEAST IMPORTANT** to you when choosing whether or not to get a mammogram?

☐ AND ☐

8. Please indicate how important each of the following features are in choosing whether or not to get a mammogram.

	Very Important	Important	Not Very Important
a) Little pain or discomfort associated with the test.			
b) Clinic staff respect my privacy.			
c) Clinic staff accurately interpret my exam results.			
d) Ability to avoid unnecessary follow-up			
e) Cost of the exam			
f) Clinic staff are friendly			
g) Waiting time at the mammogram clinic.			
h) Test results are confidential.			
i) Test results are accurate.			
j) Ease of scheduling the appointment.			
k) Ability to get an appointment that fits my schedule.			
l) Ability to protect my health.			
m) My doctor recommends that I get the test.			
n) Test doesn't miss a cancer that is there.			
o) Little risk of side effects from the test.			
p) The mammogram clinic is close to my home.			
q) I can park close to the clinic building.			
r) Clinic staff are able to answer my questions in an easy and understandable way.			
s) The clinic waiting area is comfortable.			
t) The clinic waiting area is private.			
u) The test results are available quickly.			
v) My results are presented in a way that is easy to understand.			
w) My worries and concerns are addressed by staff.			
x) Clinic staff include members of my racial and ethnic background.			

YOUR BACKGROUND

9. Your age: ☐ < 30
☐ 30 – 39
☐ 40 – 49
☐ 50 – 59
☐ 60 – 69
☐ 70 or older
10. What was the last year of school you completed?
☐ Less than high school
☐ High school graduate or GED
☐ Some college / trade / technical school
☐ College graduate
☐ Post college graduate education
11. What is your current marital status?
☐ Married
☐ Living with a partner
☐ Divorced
☐ Separated
☐ Widowed
☐ Never married
12. Are you of Hispanic or Latin origin or descent? ☐ Hispanic or Latino
☐ Not Hispanic or Latino
13. Which of the following best describes your racial background?
☐ American Indian or Alaskan Native
☐ Asian
☐ Black or African American
☐ Native Hawaiian or Other Pacific Islander
☐ White or Caucasian
14. Are you currently employed at a job for pay? ☐ Yes
☐ No
15. Have you ever been diagnosed with breast cancer? ☐ Yes. Please go to Question 16.
☐ No. Please go to Question 17.
16. Have you ever been diagnosed with a recurrence of breast cancer?
☐ Yes. STOP. Thank you for completing the survey.
☐ No. Please go to Question 18.

SCREENING AND YOU

17. This section relates to mammography (breast cancer) screening. For each statement, please indicate what you think by marking the appropriate circle. Mark only one circle for each statement.

	Strongly Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
a) I believe the chance that I might develop breast cancer is high.				
b) My close friends think that I should have a mammogram.				
c) I think that compared to other person my age, I am at lower risk for breast cancer.				
d) I want to do what member of my immediate family think I should do about mammogram screening.				
e) I believe that mammography screening can help to protect my health.				
f) I want to do what my close friends think I should do about mammogram screening.				
g) I believe that mammograms are an effective way to find breast cancer early.				
h) Members of my immediate family think that I should get a mammogram.				
i) I believe that when breast cancer is found early, it can be cured.				
j) My doctor thinks that I should get a mammogram.				
k) I want to do what my doctor thinks I should do about getting a mammogram.				

THANK YOU VERY MUCH FOR COMPLETING THIS SURVEY.

YOUR ANSWERS ARE IMPORTANT TO US.

***PLEASE MAIL YOUR COMPLETED SURVEY IN THE ENCLOSED
SELF-ADDRESSED ENVELOPE.***

SCREENING AND YOU

18. This section relates to mammography (breast cancer) screening. For each statement, please indicate what you think by marking the appropriate circle. Mark only one circle for each statement.

	Strongly Disagree	Mildly Disagree	Mildly Agree	Strongly Agree
l) I believe the chance that my breast cancer might recur is high.				
m) My close friends think that I should have a mammogram.				
n) I think that compared to other person my age, I am at lower risk for breast cancer.				
o) I want to do what member of my immediate family think I should do about mammogram screening.				
p) I believe that mammography screening can help to protect my health.				
q) I want to do what my close friends think I should do about mammogram screening.				
r) I believe that mammograms are an effective way to find breast cancer early.				
s) Members of my immediate family think that I should get a mammogram.				
t) I believe that when breast cancer is found early, it can be cured.				
u) My doctor thinks that I should get a mammogram.				
v) I want to do what my doctor thinks I should do about getting a mammogram.				

THANK YOU VERY MUCH FOR COMPLETING THIS SURVEY.

YOUR ANSWERS ARE IMPORTANT TO US.

***PLEASE MAIL YOUR COMPLETED SURVEY IN THE ENCLOSED
SELF-ADDRESSED ENVELOPE.***

Appendix F: Abstract Submission

Era of Hope 2002 Department of Defense Breast Cancer Research Program Meeting

Background: Despite general consensus that breast cancer survivors should undergo annual mammography, findings indicate over 1 in 7 women fail to receive a mammogram within two years of breast cancer treatment, and that African Americans are almost half as likely to participate in mammography screening as Caucasians.

Objectives: To develop and pilot test a survey instrument to understand what factors influence a breast cancer survivor's decision to receive mammography and whether differences exist in these factors by patient race.

Methods: Using information from the literature and four focus groups (two among African American and two among Caucasian breast cancer survivors), we are developing a mailed patient survey. In the final phase of the study, the survey is being mailed to a random sample of 100 African American and Caucasian breast cancer survivors. Using logistic regression, results from the survey will be analyzed to identify the beliefs, social influences, and preferences for mammography screening attributes, controlling for patient socio-demographic and other background characteristics (e.g., family history and comorbidities), which are related to mammography participation.

Results: Results from the literature review have led to the development of a conceptual model of mammography use among breast cancer survivors. This model, which draws heavily upon both the health behavior and economic literature, reflects our theorized importance of not only patient beliefs and social influences, but also their preferences for different mammography screening program attributes such as the accuracy of the test, the privacy of results, or the pain associated with testing. Definitive results from the focus groups and preliminary results from the mailed survey will be available at the time of presentation.